

## Chapter 2

# Epidemiology

It is easy to assume that restrictive behavior management practices are now used rarely and confined to restrictive settings, such as institutions and youth detention centers, and that such practices are things of the past as we become more enlightened and liberal and more sensitive to the rights of all people. Surely, we have reduced such practices! When journalists and advocates expose these practices at the present time, we want to believe that they represent aberrations—individual services that are badly run, staff members who are bad apples, and family members who are personally bad or dysfunctional. But maybe this is not so. Many service agencies and governments are reluctant to shine the disinfectant light of public data on the use of restraint and seclusion and often only do so when scandals, laws, lawsuits, or freedom of information requests force them to make the data public. Thus, we cannot be certain that restrictive behavior management practices have been reduced. The evidence in this and subsequent chapters show that they in fact continue to be widely used.

Justification for such cause for concern comes from the US Department of Education's (2012) restraint dataset which was publicized not through the action of the US government but rather through an advocacy group of journalists, ProPublica, a not-for-profit investigative journalist organization interested in stories with a "moral force," in collaboration with National Public Radio and exposed the widespread use of restraint in American schools in 2014 (Vogel 2014) (see ProPublica's (2014) restraint website for details).

ProPublica found that in the year 2012, there were over 267,000 reported instances of restraint and seclusion, approximately 163,000 instances of personal restraint, approximately 7600 instances of mechanical restraint, and, surprisingly, approximately 104,000 instances of seclusion. Most schools reported not using restraint or seclusion and those that did use restraint or seclusion an average of 12 times per year. A minority of schools, however, were outliers and used restraint and seclusion sometimes hundreds of times per year. They reported that, although children with disabilities are a minority, they accounted for approximately three quarters of restraint. This dataset is quite limited because the data ProPublica used

to compile it were administrative returns to the US Department of Education by schools, which, as ProPublica acknowledged, are likely to be a gross underreport. For example, several very large school districts reported that no restraint or seclusion occurred at all throughout the year for tens of thousands of children, which is unlikely to be true. Despite these limitations, it seems reasonable to conclude that restraint and seclusion are widely used in American schools today.

This chapter reviews the evidence concerning how commonly restrictive behavior management practices are used and the risk factors for their use. Their prevalence and the pattern of their use obviously change dramatically over time, from state to state, from country to country, and context to context as the society changes its views of their use, as alternative treatments are developed and as regulations and the implementation of regulations that control their use change. Thus, there will be no set answer as to what the exact prevalence of the use of restrictive behavior management practices will be. Because of this, and because of the large number of papers in this area, this chapter focuses on research over the period of 2000–2014. We review the prevalence and risk factors by population including people with intellectual and other developmental disabilities, seniors, children and adolescents, people with mental health problems, incarcerated youth, prisoners, and other populations.

## **2.1 Specific Populations**

### ***2.1.1 Mainstream School Settings***

#### **2.1.1.1 Prevalence**

There is evidence from statewide and national US databases that restrictive behavior management practices are widely used in educational settings. The US General Accounting Office (2009) cited data from California's and Texas' education systems showing that there were over 30,000 "interventions" in these two states in 1 year. Similar national data were discussed above (ProPublica 2014). Gagne et al. (2014) compared the US national school database on restraints for 2009–2010 and 2011–2012 and found little evidence of change in the use of restraints. Further, in an analysis of restraints rate per 100 students with a disability, they found that rates of restraints varied widely. Many schools did not report restraint use, whereas others reported over 80 restraints per 100 students. If the data are accurate, this may indicate widely varying practices in the use of restraint and associated preventative strategies. The only national information that was available was based on state returns to the US Department of Education, whose accuracy and completeness are unknown. Thus, there are no well-conducted studies that estimated the prevalence of restrictive behavior management practices found from either American or British sources.

### **2.1.1.2 Risk Factors**

Several American reports have focused on disparities in the use of restraint related to ethnicity and disability. These studies have all shown that children with disabilities and nonwhite children are much more likely to be restrained than children without disabilities and White children (General Accounting Office 2009; Office for Civil Rights 2012; Texas Education Agency 2009). Some put this issue of restraint in education as part of a broader literature on unequal use of disciplinary procedures in schools against boys, nonwhite children, and children with disability (Peterson et al. 2013)

### **2.1.1.3 Conclusion**

There is a surprising lack of quality evidence relating to the use of restrictive behavior management practices in mainstream educational setting. The reasons for this are unclear. It may reflect the reluctance of government agencies and private schools to open up a can of worms and subject themselves to liability issues and organizational reforms that would likely result from the publication of such data.

## ***2.1.2 Incarcerated Youth***

De Hert et al. (2011) conducted a systematic review of 10 years of research on the use of restraint and its correlates in youth in psychiatric settings. They identified seven studies. The prevalence was high and variable both for seclusion (26% of patients; 67/1000 patient-days) and restraints (29% of patients; 42.7/1000 patient-days). Risk factors included past or current aggression and/or violence, suicidal behavior, more severe psychopathology, nonwhite ethnicity, emergency admissions, out-of-home placement, and poorer family functioning.

A similar illustrative study comes from Pogge et al. (2011) who analyzed 2 years of restraint and seclusion data from a private psychiatric hospital serving 2411 children and adolescents during this time period. Seclusion included seclusion in the child's room and seclusion in an off-unit seclusion annex. Restraints were coded as short term (<15 min) and long term (>14 min). They also analyzed data on intramuscular pro re nata (PRN) medication. The most common behavioral precipitants were externalizing behavior problems, such as physical or verbal threats and attempts at self-harm. As in other populations, restraints were distributed very unevenly with only 29% of children experiencing any restraint with a mode of 1 restraint per child, but ranging up to 163 restraints in one case. Risk factors included age: Younger children had more restraints (53%) than older children (19%). Other demographic and diagnostic variables did not predict restraint use.

Thus, among patients, children and youth with psychiatric disorders are at high risk for restraint and other restrictive behavior management practices, primarily

related to externalizing behavior problems and self-injury/self-harm. Thus, as with other populations, the opportunities for reducing restrictive behavior management practices lie primarily with the management of these behavior problems and associated professional practice and administrative oversight.

### ***2.1.3 Adults with Mental Health Problems***

#### **2.1.3.1 Prevalence**

Steinert et al. (2010) conducted a systematic review of restraint databases in psychiatric facilities. They found 12 such databases which included single or multiple hospitals and national data from Norway and Finland. They found that rates of restraint and seclusion varied widely. At one extreme, Iceland, a country of some 300,000 population and only one psychiatric hospital, reported using no restraint or seclusion for decades, but replaced it with one-on-one nursing staff. In contrast, Austria reported that 36% of patients were exposed to restraint and seclusion, and The Netherlands used seclusion with 12% of patients for a mean duration of 294 h! Steiner et al. suggested that the high rates of seclusion in the Netherlands might reflect strong legal prohibitions against the use of involuntary psychotropic medications, except in cases of emergency. Thus, restraint and seclusion are commonly used in psychiatric hospitals, and practices vary very widely from country to country.

The rate of restraint varies dramatically over time in some states reflecting the presence programs to reduce restraint and continued commitment to do so. For example, Smith et al. (2005) reported very large reductions in restraint in the Pennsylvania state hospital system between 1990 and 2000. The rate of restraints fell from 4.2 to 0.3 episodes per 1000 patient-days. The mean duration of seclusion decreased from 10.8 to 1.3 h. The rate of restraint fell from 3.5 to 1.2 episodes per 1000 patient-days. The average restraint duration fell from 11.9 to 1.9 h. Thus, the rates of restraint and seclusion vary considerably over time depending upon the quality of the programs used to reduce restraint.

The prevalence among patients in forensic psychiatric facilities may be especially high. Haw and Wolstencroft (2014) reported that in an English secure forensic institution with 242 patients fully 73% had prescriptions for PRN medications. Within the previous 2 weeks alone, some 542 doses were administered to 37% of the patients. This resulted in 11% receiving high doses of antipsychotics and 20% receiving polypharmacy due to PRNs. Further problems included absent or vague documentation of the reasons for PRN medication.

#### **2.1.3.2 Risk Factors**

Some studies have also found that factors related to the facility, rather than the patient, also predict restraint use. For example, Lay et al. (2007) found wide variations between different Swiss psychiatric hospitals in their use of restrictive proce-

dures, but simple structural variables, such as hospital size and staff workload, did not predict the use of restrictive procedures, although van Der Schaaf et al. (2013) found that some physical and architectural features, such as special safety features and access to private space, predicted restraint use. More specific programmatic variables related to restraint use were identified by Smith et al. (2005) who found that in Pennsylvania's psychiatric hospital system that longer restraints occurred at night and restraints were used more frequently during the week.

### **2.1.3.3 Conclusions**

Restrictive behavior management practices, especially restraint and seclusion, are commonly used in psychiatric hospitals and may be used especially liberally in forensic settings. Wide variation in their use occurs between hospitals, over time and across different countries. These variations reflect differences in policy from country to country and programmatic variables correlated with time of day, day of week, and efforts to reduce restraint and seclusion over time.

## ***2.1.4 Persons with Intellectual Disabilities***

### **2.1.4.1 Prevalence**

Table 2.1 summarizes several studies of the prevalence of restrictive behavior management practices in children, adolescents, and adults with Intellectual Disabilities. The reported prevalence is quite high. For example, Emerson (2002) reported in his study 3 that just over 10% of a large sample of children with Intellectual Disabilities experienced physical restraint and just over 10% experienced seclusion. Most of the data in this table related to certain at-risk subsamples, such as individuals with challenging behavior and/or those in residential settings. Among these groups, the rates of restrictive behavior management practices are quite high ranging as high as approximately two thirds, although figures of one third to a half were commonly reported. A notable observation comes from Allen et al. (2006) who reported high rates of physical restraint use in some families. Most of these families also reported receiving no or minimal professional assistance, despite the severity of their children's behavioral issues. Thus, within this population, certain subgroups, including some families, have very high rates of restrictive behavior management practices in contemporary services.

Other restrictive procedures, such as PRN medications, are also commonly used in adults with Intellectual Disabilities. For example, Delafon et al. (2010) reported on the prevalence of psychotropic medication in assessment units in Leicestershire, UK, in a sample of 119 individuals over a 1-month period. They found that approximately three quarters of people with Intellectual Disabilities were prescribed psychotropic medication, approximately one quarter also experienced PRN psychotropic medication, and approximately 40% experienced polypharmacy, mostly due to the use of PRN medication.

**Table 2.1** A summary of selected papers on the prevalence of restraint and other restrictive behavior management practices in children and adults with Intellectual Disabilities

Reference	Methods	Results
Murphy et al. (1993)	Total population survey of people with intellectual disability and self-injury ( $N=616$ )	13% of sample who were self-injured wore protective devices or mechanical devices. Nearly half used psychotropic medication, but only 2% had any formal psychological intervention
Emerson et al. (2000)	$N=500$ adults with Intellectual Disabilities in residential settings	Of 53% of the sample who had moderate or severe challenging behavior, 44% experienced physical restraint, 35% sedation, 20% seclusion, and 3% mechanical restraint
Emerson (2002): Study 1	$N=107$ children and adolescents with Intellectual Disabilities and challenging behavior	67% “usually” or “sometimes” managed with physical or mechanical restraint, seclusion or sedation
Emerson (2002): Study 2	$N=68$ children and adolescents with Intellectual Disabilities and challenging behavior	46% had physical restraint, 67% had seclusion 2% had sedation, and 4% had medication
Emerson (2002): Study 3	Of 909 children, data on challenging behavior were collected on 656. Of these 42% had at least one form of severe challenging behavior	28% had physical restraint, 32% had seclusion, 1% had sedation, and 3% had mechanical restraint. The corresponding figures for all children were 12, 13, <1, and 1%, respectively
Feldman et al. (2004)	Surveyed 625 clients with challenging behavior in Ontario. Included 96 agencies institutional and noninstitutional settings. Used open-ended questions about how providers managed challenging behavior	12% had physical restraint, 12% had confinement time out, and 6% had mechanical restraint. Many behavior management practices, including restrictive behavior management practices were informal and undocumented
Allen et al. (2006)	$N=72$ families with children with severe challenging behavior. Data were gathered via postal questionnaire	88% used physical restraint and 21% used it frequently
Sturmev (2009)	Analyzed English restraint data from Healthcare Commission and Commission for Social Care 2007 data. $N=509$ community residential units run by the National Health Service with 3902 residents	Approximately, 80% of units used some form of restraint, 45% used physical restraint, 9.5% reported using seclusion, 8% reported using mechanical restraint, 6% reported using other restraint, and 81% reported using PRN medication. A minority of units used restraint at much higher rates than average, and a minority of individuals experienced high rates of restraint

**Table 2.1** (continued)

Reference	Methods	Results
Devreau and McGill (2009)	<i>N</i> =542 managers of residential National Health Service and social service run residential units with 25 % response rates	29% reported use of breakaways for grabs and bites, 26% blocks for punches and kicks, 12% restraint while resident was sitting, and 5% while resident was lying on floor
McGill et al. (2009)	Used an 8-item survey of <i>N</i> =268 individuals from 100 staff respondents participating in conferences. Settings included residential services (37%), 30% in schools 8% from day services, and the remainder from other services. Respondents included nurses (39%), teachers (39%), and social work (6%)	22% of clients used protective devices, 50% used PRN medication, 27% used seclusion, and 84% used physical restraint during the previous year. 10% of clients experienced physical restraint daily
Allen et al. (2009)	<i>N</i> =901 children and adults with challenging behavior and Intellectual Disabilities who were part of a larger sample. Data collected by a screening questionnaire	36% experienced restraint, 22% seclusion, and 27% PRN medication
Chaplin et al. (2009)	Residents ( <i>N</i> =68) of a 6-bedded secure assessment and treatment unit over a 6-year period	49% experienced de-escalation, 35% restraint and medication, 23% sanctions or surveillance (e.g., removal of dangerous objects), 20% “external assistance,” and 20% were transferred to other units
Finn and Sturmey (2009)	<i>N</i> =81 service users of a day program for adults with Intellectual Disabilities and mental health disorders and/or challenging behavior	13 consumers accounted for 100% of uses of restraint. Incidents included 31 removals, 1 wrap, 7 take downs, and 92 time outs
Merineau-Cote and Merin (2012)	<i>N</i> =81 adults living in community settings. Data were collected using a mail survey	All restrictive measures—63.0%; seclusion—44.4%; physical restraint—42.0% physical restraint; and mechanical restraint—27.2%

*PRN pro re nata*

**2.1.4.2 Risk Factors**

Several studies have robustly found that restraints are concentrated in a small number of individuals with Intellectual Disabilities (Finn and Sturmey 2009; Luiselli et al. 2005; Sturmey 1999; Sturmey 2009; Sturmey and McGlynn 2002). For example, Sturmey (1999) found that in a sample of 300 residents with intellectual dis-

abilities, only 33 clients accounted for all short-term restraints, such as those related to aggression, and 11 clients accounted for all long-term restraints, such as those related to chronic severe self-injury and pica. Thus, approximately 15% of clients accounted for 100% of restraints. Finn and Sturme (2009) made similar observations when they presented histograms showing that, in a sample of clients attending a day program, only 22% of consumers accounted for 92% of restraints with a handful of consumers having much higher rates of restraints than all other consumers. Thus, there is good evidence that individual differences are large, raising the question as to what might account for these individual differences. Similar data can be presented for differences between settings. For example, restraints are reported much more frequently in residential care than in family setting.

Table 2.2 summarizes a number of studies that have examined predictors of restrictive behavior management practices in people with Intellectual Disabilities. Studies have reported predictors that included demographic and diagnostic variables, behavior problems, and environmental variables. This table shows that restrictive behavior management practices are often predicated by externalizing behavior disorders, such as aggression and injury to others, but not internalizing behavior disorder, such as anxiety and withdrawal. Several studies reported that those diagnosed with autism spectrum disorders were more at risk, although the degree of intellectual disability produced different outcomes in different studies, perhaps because externalizing behavior disorders are more dangerous in physically able individuals who are more likely to have mild intellectual disability, but self-injury is more likely to occur in individuals with profound intellectual disability. One study also found that limited communication skills were also a significant predictor. Some studies reported that high rate behaviors such as stereotypy also predicated restrictive behavior management practices. Behavior severity and indirect measures of behavior severity, such as out of geographical district placement and presence of a behavior support plan, and detention under the British Mental Health Act, are also significant predictors of restraint use. There is some evidence that the failure to implement positive procedures, such as redirection (Chaplin et al. 2009), predicts use of more intrusive management strategies, such as physical restraint. When reviewing these data, it is important to keep in mind that some studies did not distinguish different types of restrictive practices. This might be important as, for example, Sturme (1999) found that short-term restraints were predicted by hurting others, but long-term restraint was predicted by hurting self.

In contrast with diagnostic and demographic variables that practitioners cannot change, environmental variables, which are manipulable, strongly predict the use of restrictive practices. For example, Luiselli et al. (2005) analyzed the type of activities that predicted the use of physical restraint in a community-based residential school. They found that seat work accounted for nearly 20% of all physical restraints with leisure activities alone, leisure activities with others, transition, chores, and preferred activities, each accounting for approximately 8–11% of incidents of physical restraint. Finn and Sturme (2009) replicated the effects of environmental variables in predicting restraint use in adults with Intellectual Disabilities in a day treatment program. Although such data show that environmental events pre-

**Table 2.2** Risk factors associated with restraint and other restrictive behavior management practices

Reference	Risk factor
Oliver et al. (1993)	More severe challenging behavior, multiple forms of challenging behavior, younger, greater impairments than those without self-injury
Sturmev (2009)	Short-term restraint frequency and duration predicted by hurting others, but not demographic or other behavioral variables Long-term restraint was predicted by hurting self
Sturmev et al. (2005)	Impulse control disorder Aberrant Behavior Checklist Irritability DASH-II Elimination disorder Effect sizes were small
Sourander et al. (2006)	Autism
Robertson et al. (2005)	Restrictive management practices were more likely in community settings, where there were many people with challenging behavior rather than few people with challenging behavior
Tasakanikos et al. (2007)	Externalizing behavior problems, such as aggression and pestering staff independently predicted the use of antipsychotic medication and psychiatric services
McGill et al. (2009)	The following demographic variables predicted physical interventions (including mechanical restraint, PRN medication, and seclusion): young, male, not legally restricted, and autism. The following behavioral variables predicted physical interventions: aggression (87%), intense displays of emotion (79%), and least predictors were inappropriate sexual behavior (30%), antisocial behavior such as lying and cheating (32%), and inappropriate personal habits (36%). Predictors varied by type of restrictive behavior management practices
Allen et al. (2009)	Detention under the Mental Health Act (restraint and sedation), more severe challenging behavior (seclusion), destructive behavior (restraint and seclusion), placed out of geographical area (seclusion), and had behavior plans (restraint and seclusion)
Emerson (2002) Study 1	More severe challenging behavior, less severe intellectual disability and more restricted expressive communication (physical restraint), and greater self-care ability and more stereotyped behavior (seclusion)
Emerson (2002) Study 2	Injury to other children (restraint)
Emerson (2002) Study 3	Irritability, less anxiety, more conduct disorder and attending special education (physical restraint) and isolated/ritualistic behavior, attending special education, more conduct disorder, more self-injury, more irritability older and Black British (seclusion)
Webber et al. (2010)	Participants on compulsory detention were more likely to be seclusions (44%) versus a match control group (5%)
Webber et al. (2012)	Better quality behavior support plans predict less restraint
Webber et al. (2014)	Seclusion predicted by individual variables, such as age, autism, and psychiatric disorders and organizational variables, such as using institutional or community residential services and location of services

dict restraint use, they are relatively crude, in that they do not identify the precise functions of stimuli involved in a high-risk situation. They may be quite useful, however, in that they may direct clinicians where to look when conducting a more detailed functional behavior assessment and may be helpful in designing effective behavior support plans. For example, Luiselli et al. (2000) constructed behavior support plans using antecedent interventions to greatly reduce the use of restraint in two adolescents with pervasive developmental disorder compared to their existing behavior support plan.

People with Intellectual Disabilities may be especially vulnerable to the use of restraints during medical, dental, nursing procedures, and physical and occupational therapy. Newton (2009) reviewed the use of restraints during dental procedures and found a wide range of restrictive practices used during dentistry with people with Intellectual Disabilities. A subsequent survey revealed that although dental practitioners reported being confident in behavior management issues, many general practitioners' knowledge of nonrestrictive management practices was limited, although specialists reported somewhat more non-pharmacological methods of behavior management (Humza Bin Saeed et al. 2012).

## Genetic Syndromes

Individuals with certain genetic syndromes, such as Prader-Willi, Cornelia de Lange, and Smith-Magenis syndromes, which are associated with severe self-injury, are at especially high risk for restrictive behavior management practices. For example, Anderson and Ernst (1980) surveyed behavior management practices for 40 individuals with Lesch-Nyhan syndrome, a rare genetic syndrome associated with multiple forms of severe self-injury, such as lip and finger biting. They found that nearly half were restrained throughout the day, and about 80% were restrained at least half of the day. Sixty percent had teeth extracted to prevent self-biting. People with Prader-Willi syndrome are often subjective to environmental restrictions, such as locked refrigerators and kitchens, because they often eat very large amounts of food and are severely obese placing them at risk for serious cardiac and other health problems and reduced mortality.

### 2.1.4.3 Conclusion

In sum, although we do not have good demographic data because of the problem of adequately defining and sampling from a population of individuals with Intellectual Disabilities, there is strong evidence that certain groups, service, and perhaps certain families are at high risk of frequently using restrictive behavior management practices. Similarly, a small number of clients and a few settings account for the majority of restraints and seclusions. The strongest and most consistent predictors of restrictive behavior management practices are externalizing behavior problems,

such as aggression, tantrums, and self-injury. There is good evidence, which is consistent with the literature on functional behavior assessment, that environmental variables predict use of restrictive behavior management practices on a case-by-case basis and that information can be a useful part of assessment that leads to an effective behavioral support plan.

There is evidence that deficiencies in services, such as the absence of technically adequate behavior support plan and its effective implementation, also predicts the use of restrictive behavior management practices (see Chaps. 10 and 11) which is consistent with many studies that have shown that implementation of an effective behavior plan may reduce their use. Thus, if services wish to reduce restrictive behavior management practices, they should identify and focus on a specific number of individuals and settings, provide effective, evidence-based interventions for externalizing behavior and self-injury, and provide adequate support and oversight for all staff, including professional staff, to do so.

### **2.1.5 Seniors**

#### **2.1.5.1 Prevalence**

Services for seniors have varied dramatically from place to place and time to time in their use of restraints. Hence, restraints might be used routinely in one state and rarely in the neighboring state. Likewise, in response to Federal or other legal initiatives (Hawes et al. 1997) or even under their own initiative, services for seniors may change from routine, widespread use of restraints to nearly eliminating them. Thus, individual figures quoted in should be considered in the context in which the data were collected, but should not be generalized to other contemporary contexts.

There are a large number of empirical studies of the prevalence of physical restraints in nursing homes. Here, we consider two reviews. Dube and Mitchell (1986) reported that restraint was used in nearly 100% of nursing homes. The proportion of residents restrained varied widely from 19 to 85%. More recently, Schussler et al. (2014) also reported widely varying figures. These authors conducted a systematic review of characteristics of nursing home residents with dementia. The review discussed seven studies published between 2003 and 2013. The prevalence of restraints ranged from 10 to 59%. Six studies found that the most common form of restraint was bed rails. Figures varied in part due to the definition of restraint and the time period over which restraint was reported (e.g., last 24 h vs. last month).

Psychotropic medications are also used widely in nursing homes, predominantly for behavior management. Simoni-Watsila et al. (2014) using a 5% sample of Medicare data from 2007 found that two thirds of the sample used at least one psychotropic medication with nearly 60% taking antidepressants, approximately one third taking antipsychotics, and nearly two thirds taking psychotropic medication from at least two different classes of psychotropic medication.



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